

Welcome back to the Kids Crusaders Corner. My son Nick was 10 months old when we were finally given a diagnosis of Cerebral Palsy instead of the blanket terminology of “developmentally delayed”. A weight was lifted and in the same second it felt like the weight of the entire universe came crashing down and it was impossible to breathe. We had no idea what the future held, no idea what he would or wouldn’t do. What we had were shattered hearts and dreams of all the things we always thought he would do as a little boy.

I began writing as a way to outlet some of the pain. I chose at the time to write from my son’s perspective, as if I were him. The following is an article I wrote when he was 18 months old. We lived across the street from a park that has a baseball field and every Saturday we would watch out the window as the kids laughed and ran and played.

“Hi, my name is Nicholas Fioravanti (better known as Nick by those who love me, which is just about everybody---brag, brag). I am 18 months old and I have Cerebral Palsy. Big deal, right? In a way it really is a big deal, and in a way it’s not.

I’ve been through a lot during these last 18 months, and the fun is just beginning (so they tell me). “Therapy” is my middle name. I get so tired of being pushed one way and pulled the other. The way I figure is, if my body wanted to sit up, it would! Right? Wrong. Back to therapy. I do try really hard, though, and I am usually very tired afterwards. And therapy doesn’t end at school. Oh no, I have my Mom and Dad breathing down my neck all the time, saying “pick up your head honey,” “don’t hyperextend” or “use your hands and not your feet.” I’ve gotten to the point where if I could talk, I’d probably say something like “Dad, I know you don’t want to do this, and I certainly don’t want to do this, so why not go play baseball instead?” Nice thought, but back to reality. I can’t walk, so forget about traditional baseball. But (and here’s where it gets better), what about imaginary baseball?

Not too long ago, Mom, Dad and I went across the street to the baseball diamond. My Dad carried me to home plate. We waited for the first pitch, then WHACK. We were off and running. We made it to second base. I squealed, my Dad laughed, my Mom thought we were both crazy and I’m sure the neighbors were probably talking. The next hit was a line drive right down the center and we made it to third. The last hit was a pop fly and we decided to steal home. We ran so fast the wind whistled through my hair. It was a race against the ball. The invisible umpire yelled “Safe!”, and Dad confirmed it as he gave me a hug and spun me around. “We’re safe!” he kept saying as he hugged me tight. And let me tell you, I’ve never felt safer than at that very moment. With my Dad’s arms around me, love and laughter filled the air, and a memory was made.

I don’t know who won the game that day; I think there are still a lot of innings left to be played. I know I am a winner, though, because I don’t quit. And because I have parents that share the fun things with me in life, who believe in me, parents who treat me like a kid and not like a disability. And they love me unconditionally.”

And that was the article I wrote when Nick was 18 months old and I was struggling alone with my grief, trying to find answers. I was 25 years old, and the world was so much bigger than I ever imagined it could be. We continued to play with Nick and try everything that other kids would try. It was easier when he was 18 months old in some respects. He was much smaller and easier to move around! Right now at 6'1" and 143 pounds, there are no running bases with him. However, if there's a will, there's a way. And if Nick wants to try something, my answer is always yes. The world is still so much bigger than I ever imagined it could be, however I am no longer struggling (at least not every day!), and more importantly, through time and never giving up, I discovered that I was never "alone" in my journey.

Don't let life ever stop you from loving and laughing and filling the air. Make memories. One day you will look back and be glad that you did. And always remember, your journey is unique but you never have to feel alone.

Peace and love until next month.

Julie